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RESEARCH

Being a Parent of an Individual with Rett syndrome – An Explorative Study of Parental Experiences Across Different Ages and Phases of Life

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Abstract

Parents of individuals with multiple disabilities, including those with Rett syndrome (RTT) provide prolonged caregiving and take on lifelong responsibilities for their child. Therefore, the parents' ability to develop and sustain wellbeing throughout the years is crucial. To support them in this, knowledge about what affects them in different life phases throughout the years is important but limited. We aimed to explore the experiences of parents of individuals with RTT across different ages and phases of life, and how these experiences have affected them and their wellbeing. Using a phenomenological hermeneutic approach, we conducted an exploratory qualitative interview study with 25 parents of various ages of 12 individuals with Rett syndrome. The parents experienced a lifelong sense of having the principal responsibility for their child's health, wellbeing, and quality of life, which affected them diversely, depending on the life phase they were going through. Over time, the parents accumulated experiences in different areas and situations that helped them manage similar future challenges. However, over time the extensive caregiving demands could also lead to exhaustion. Providing demanding care for many years, continuously advocating for the child, and witnessing the child's struggles over time affected the parents' wellbeing, albeit differently across life phases.

Keywords Parents · Caregiver · Rett syndrome · Wellbeing · Multiple disabilities · Qualitative study

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Introduction

Rett syndrome (RTT) is a genetic neurodevelopmental disorder that primarily affects females and leads to severe multiple disabilities (see Table 1) (Amir et al., 1999; Neul et al., 2010). It is associated with various medical complications, including movement disorders, epilepsy, scoliosis, gastrointestinal and respiratory difficulties, and feeding issues (Bao et al., 2013; Downs et al., 2008; Kerr & Julu, 1999; Neul et al., 2010; Smeets et al., 2019). These challenges necessitate comprehensive care, similar to that required by individuals with multiple disabilities in general (Geuze & Goossensen, 2021; Nieuwenhuijse et al., 2019).

Parents of individuals with RTT or other multiple disabilities undertake extensive caregiving responsibilities including daily living activities such as feeding, toileting, bathing, dressing, and assist them in getting up and moving around. They administer medicine, handle medical devices, and comfort their child during seizures, coughing fits, and screaming or crying spells (Geuze & Goossensen, 2019, 2021; Luijkx et al., 2017). Many provide around-the-clock care, leading to sleep deprivation and exhaustion (Rousseau et al., 2020; Tadema & Vlaskamp, 2010). Additionally, they must advocate for their child, and interact with professionals, and apply for aids and social services (Currie & Szabo, 2019; Ryan & Quinlan, 2018). This comprehensive parenting responsibility and care work can lead to exhaustion (Geuze & Goossensen, 2019; Rousseau et al., 2020; Woodgate et al., 2015), burn out (Patty et al., 2024), and increased risk of experiencing stress, anxiety, and depression (De Gaetano et al., 2022; Griffith et al., 2011; Jakobsen et al., 2020; Robowtham, 2011; Scherer et al., 2019; Wulffaert et al., 2010).

Unlike typical parenting roles, which evolve as children gain independence, parenting an individual with multiple disabilities remains a lifelong responsibility, as individuals with multiple disabilities never become able to take care of themselves (Rydzewska et al., 2021; Schonewolf-Greulich et al., 2017). Even when the child moves into a group home, the parental responsibility and advocacy persists (Band-

Table 1 Characteristics of Rett syndrome (Fehr et al., 2011; Fu et al., 2020; Neul et al., 2010)

Main criteria
• Comprehensive or complete loss of acquired spoken language
• Comprehensive or complete loss of acquired purposeful hand skills
• Gait abnormalities: dyspraxic or absent
• Hand stereotypies
Supportive criteria
• Breathing disturbances when awake
• Bruxism when awake
• Sleep disturbances
• Abnormal muscle tone
• Peripheral vasomotor disturbances
• Scoliosis/kyphosis
• Poor growth
• Small, cold hands and feet
• Inappropriate laughing/screaming spells
• Diminished response to pain
• Intense eye communication

Winterstein & Avieli, 2017; Namkung et al., 2018). Research indicates that there can be a negative cumulative effect on the parents' wellbeing. However, what specifically contributes to this effect is underexplored (Macdonald & Callery, 2008; Robowtham, 2011). Although limited, existing research about parents of individuals with multiple disabilities in different life phases suggests that parents face distinct challenges. For instance, older parents must balance caregiving with their own aging (Dillenburger & McKerr, 2011; Thackeray & Eatough, 2015; Walker & Hutchinson, 2018). Given that the wellbeing of individuals with multiple disabilities is linked to the parents' ability to continue carry out their parental responsibilities (Aran et al., 2007; Rosenbaum, 2011), understanding the parents' experiences with being a parent and how it affects them in different ages and life phases is crucial.

Most studies on parenting individuals with multiple disabilities rely on quantitative methods and focus on mental health outcomes (Larsen et al., 2024). However, first-person descriptions from in-depth qualitative research are essential to further uncover the full complexity of parental experiences (Brinkmann, 2022). Therefore, by using RTT as a signature example, the aim of this study was to explore parents' experiences of being a parent of an individual with RTT across different ages and phases of life and how it has affected them and their wellbeing.

In this study, we understand wellbeing as the parents' subjective experiences and inner perceptions, encompassing their positive and negative understandings and emotional responses to what they are experiencing (Martela & Sheldon, 2019). It highlights their appraisal of challenges and potential gains, which can affect how they experience being affected by being a parent of an individual with RTT.

Methods

Design

To gain a deeper understanding of parents' experiences, we conducted an exploratory qualitative study using semi-structured interviews with parents of individuals with RTT at different ages and phases of life. We applied a phenomenological hermeneutic approach (Dibley, 2020; Lindseth & Norberg, 2004, 2021), which allowed us to explore both the meaning of their parenting experiences and how it has affected them and their wellbeing. The phenomenological aspect of this approach enabled us to capture the lived experiences of parents with different ages and across different life phases, and what they perceived had affected them and their wellbeing throughout the years. The hermeneutic aspect involved interpreting their narratives to seek deeper meanings and patterns in their experiences. This process helped us to better understand how being a parent of an individual with RTT has influenced them and their wellbeing over time and in the different life phases (Lindseth & Norberg, 2004, 2021).

Setting

The study was conducted at the Danish Center for Rett Syndrome (CRS), which is a national expertise center that offers lifelong assessment and counselling to indi-

viduals with RTT, their families and local professionals. In February 2025, 126 individuals were diagnosed with RTT in Denmark, of which about 80% of them were followed by CRS on a regular basis.

Participants

To capture a wide range of experiences, we aimed to recruit parents who: (1) were in different phases of their parental life, (2) either lived together or were divorced/separated or widowed, and (3) lived/did not live together with their child with RTT (4) were of different sexes. We assumed these variations could influence the kind of care tasks, responsibilities, life-situation each parent faced, and the parents' experiences, their perceptions of being a parent, and how this has affected them and their wellbeing.

Inclusion criteria: parents of individuals > 10 years of age with clinically and genetically (*MECP2* variants) verified RTT. *Exclusion criterion*: parents who could not understand and speak Danish . The parents were recruited through CRS, where they were sent an invitation to participate in the project by the CRS physician. If they were interested in participating, the first author (JLL) contacted them and provided further information about the project before the parents made the final agreement to participate.

The participants was included using a purposeful sampling approach (Patton, 1990). Twenty-five parents of 14 individuals with RTT were approached. Twenty of them agreed to participate, representing 12 individuals with RTT (Table 2).

Table 2 Description of participants and their child with RTT

Parents ($n = 20$)		n
Sex		
	Female	12
	Male	8
Age (years)		
	40–50	8
	51–60	6
	61–70	2
	> 70	4
Cohabitation status		
	Cohabiting with the other parent	15
	Cohabiting with new partner	3
	Living alone	2
Individuals with RTT ($n = 12$)		
Age (years)		
	10–20	5
	21–30	3
	31–40	0
	41–50	2
	51–60	2
Living accommodation		
	With parents	7
	Group home	5

Data Collection

We used an interview guide (Appendix A) with open-ended questions on the parents' experiences of their lives as parents. The interview guide consisted of three parts: (1) Their perceptions of their current parenting role, responsibilities, and challenges (2) A timeline drawn by the parents where they were to note pivotal situations or experiences they deemed had been essential for them as parents, and how it had affected them, and (3) Reflections on their future parenting role.

The first author (JLL) conducted 13 face-to-face interviews between March and June 2023. First, she carried out two pilot interviews, to check if the structure of and questions used in the interview were feasible and relevant. Based on these interviews, it was found that no major changes needed to be made. Subsequently, JLL conducted a further 11 interviews.

For parents who lived together, it was optional whether they wanted to be interviewed together or separately. Accordingly, seven interviews were conducted with the parents together, while six of the interviews were conducted with one parent alone. The participants could also choose whether they wanted to be interviewed at home, at the Rett center or at a different place, according to their choice. The interviews were audio-recorded and transcribed verbatim. When an interview had been conducted, JLL's immediate thoughts and reflections from the interview were documented as field notes.

Data Analysis

The data analysis was carried out using the phenomenological hermeneutic method developed by Lindseth and Norberg (Lindseth & Norberg, 2004, 2021). Their method consists of three steps which is: (1) a naïve reading of the interviews (2) a structural analysis of the data (3) providing a comprehensive understanding of the phenomenon through reflections in relation to relevant literature. An overview of the analytical process is displayed in Table 3.

Table 3 An overview of the analytical process

Step	What was done	By whom
1	Naïve readings of the transcribed interviews	JLL, HH, LEN
2	Structural thematic analysis where the transcribed interviews were divided into meaning units	JLL
2	Forming emerging main themes and sub-themes	JLL
2	Discussions about emerging themes and sub-themes	JLL, HH, LEN, ELT
2	Relating themes were merged into overarching themes and subthemes through an iterative analytical writing process	JLL, LEN, ELT, HH, MS, AMB
3	Discussion of the findings in relation to relevant literature	JLL, LEN, ELT, HH, MS, AMB

When the research group agreed upon the themes, they were presented to a stakeholder group consisting of three mothers and one father of children with RTT, at different ages and phases of their parental life. Following the presentation, the parents were asked to reflect individually on the findings and discuss them with JLL and the other parents in plenum. Their reflections and discussions were used to validate the findings and decide on the findings that were the most important to focus on.

To increase the trustworthiness of the study, we included parents of individuals with RTT who had diverse living conditions and clinical levels of RTT. We used researcher triangulation to ensure rich data reflections by including researchers with various backgrounds in the research team: an educational psychologist, a pediatric physical therapist, a child neurologist, two pediatric nurses, and a medical anthropologist. As such, the findings were developed in an iterative process where they were discussed in the research group. The richness of the reflections was further enhanced through discussions of the findings with the stakeholder group.

To strengthen the transferability and the transparency, we have made thick descriptions of the research settings, data collection, and the analytical process. Before the data collection, JLL wrote down her preunderstandings of the field, based on her clinical experiences with families where one of the members had RTT.

Ethical Considerations

All the parents signed an informed consent form, and we obtained the required approvals to conduct the interviews from the Danish Data Protection Agency of the Capital Region (reference no. P-2022-754) and the National Committee for Health Research Ethics (reference no. F-23008139). Asking parents to talk about family hardship caused by having a child with severe multiple disabilities framed their family life in a particular way and we offered the parents that, if the interview gave rise to difficult thoughts and feelings, a follow-up session with JLL or another educational psychologist from the Rett center could be arranged. None of the participants requested a follow-up session.

Results

From the interviews, eight themes emerged (Fig. 1.). They were categorized into two types of experiences: *Life phase experiences* and *Repeating experiences*.

Life phase experiences referred to experiences affecting the parents that were linked to a particular life phase in the parents and their child's life. *Repeating experiences* arose from situations that occurred repeatedly throughout a long life as parents. Some of these recurring situations could be particularly challenging, while others may have seemed manageable at first. However, the repetitive nature of these experiences could contribute to perceived burden, burn out, or frustration over time. Each time parents encountered a repeating experience, the current experience built upon their past experiences. This accumulation of repeating experiences affected how the parents were feeling and reacting both in the present and in future similar situations.

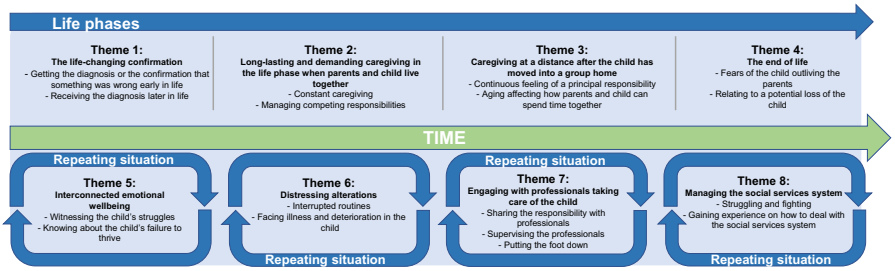


Fig. 1 Overview of themes and subthemes distributed in type of experiences

Life Phase Experiences

Theme 1: The Life-Changing Confirmation

Getting the Diagnosis or the Confirmation That Something Was Wrong Early in Life

When the parents received the diagnosis of RTT early in the child's life, or when their concerns about their child's development were confirmed, they described it as an emotional and difficult time, marked by shock, grief, worries, and sadness.

Talking about this in retrospect could still be emotional for some of them.

> *"Dad: So, I would put it this way that, ehm, it was of course devastating,*
>
> *Mom: Yeah.*
>
> *Dad: All those dreams you had for her. Well, it was, ehm, ….and it has taken years [to get over]."*.
>
> (Parents interview 13)

With the confirmation of something was wrong, the parenting role changed dramatically into something the parents had not anticipated and felt unequipped for. While going through this period, the parents also had to comprehend the consequences of the diagnosis for the child's life and the future life of the family. In addition, they had to learn to navigate a new world of service systems, e.g., the social services system, which could be challenging and further stressful for them.

Receiving the Diagnosis Later in Life

Some of the older individuals with RTT had not received their diagnosis until several years after they had developed symptoms of RTT, because the diagnosis was still unknown to many pediatricians at the time. For the parents of these individuals, receiving the diagnosis later in the child's life had been a relief, because it provided an explanation for the condition, symptoms, and the comorbidities the child was displaying.

"Mom: It was a relief to learn she had Rett, yes.

Dad: Yes, it wasn't, it wasn't a frightening surprise. It was like…well, then you had sort of something to relate to."

(Parents interview 4)

Furthermore, some of these parents experienced that having an exact diagnosis opened the doors to getting help from the social services system.

Theme 2: Long-Lasting and Demanding Caregiving in the Life Phase When Parents and Child Live Together

Constant Caregiving

When the individual with RTT was living at home, the parents felt they had the principal responsibility for the health, wellbeing, and quality of life of the child, and fulfilling the child's needs was the parents' highest priority. Everything was planned around the child, and their everyday life was filled with demanding and time-consuming caregiving tasks, some of which had to be carried out at night. Furthermore, the parents had a lot of administrative responsibilities relating to the child, e.g., applying for aids and support, contacting professionals, or ordering equipment. The number and types of daily caregiving tasks could make the parents feel like they were always at work, no matter if they were at work or at home.

"[…] our home has always been my working place. I have never had time off when I got home from work."

(Mother interview 11)

The parents found it straining and exhausting to perform the multiple demanding caregiving tasks day after day and night after night. Some of the parents also described that, over the years, they became increasingly tired and fed up with having to do it. In some cases, it could even challenge their ability to enjoy being together with their child.

"Right now, we need to only care for her rather than take care of her. You know…I would say we're a bit fed up with all that practical stuff. So, now, we just want to do the fun stuff with her[…] Now we've taken care of her for so many years."

(Mother interview 10)

The parents described that they felt they frequently exceeded their mental capacity when providing daily care, which could lead to a growing sense of exhaustion over time. Some had overextended themselves for years but placing their child in a group

home while being a minor was also something they wanted to avoid. Therefore, due to their unconditional love for their child, they continually found ways to persevere and provide the comprehensive care. However, for some this could end up leading to experiences of extreme exhaustion, where everything related to their child constantly reminded the parents about their demanding caregiving responsibilities, which triggered their feelings of exhaustion even more.

> *"Well, I had her "up to here" [pointing to her throat], you know she made me feel nauseous. I had periods where just the smell of her, I couldn't stand it. Even if she wasn't home. You know, if there was just a blanket or something that smelled of her[…] Because I just felt that I never had time off, you know, I missed that […]my resources were emptied, you know, my quota was used at that time[…] and then I thought I would go on with it, argh, we'll give it a year or two, because it was also important, this [finding the right place for her to live]. And it ended with [4–5 years] before she moved away from home"*
>
> (Mother interview 11)

Managing competing responsibilities

In their daily life, the parents had to balance the demanding and time-consuming responsibilities for the child with RTT with other competing responsibilities related to siblings or work, which could be rather stressful for the parents.

> *"Dad: Then the challenge is if the home care assistant calls at the last minute and cancels.*
>
> *[…].*
>
> *Mom: […] and it is just unfortunately the day where we both get off later than three o'clock, and [dad's name] is on the closing shift, so it is always me that has to take time off from work in a rush and, in a hurry, close down and rush out the door, and that is a drag, but you know…".*
>
> (Parents interview 7)

Over the years, further competing and demanding responsibilities that did not relate to the child with RTT could occur, for example aging grandparents or the spouse's or one's own medical problems. For the parents these competing responsibilities could add yet another time-consuming and mental burden on them and decrease their mental resources.

> *"… and [name of father-in-law] was really sick, and it just kept on going. It was just a part of these things that had to be solved, and these routines that also just kept on going. […] so we had [name of the child] who didn't sleep, and the*

boys [siblings] needed to be taken care of, and then there was a parent-teacher meeting at school, and we both had our jobs. It was just constantly, you know."

(Father interview 2)

Theme 3: Caregiving at a Distance After the Child has Moved Into a Group Home

Continuous Feeling of a Principal Responsibility

After the child had moved out of the parental home, the parenting role and responsibility changed. The parents were no longer responsible for the daily caregiving. Even so, the parents continued to feel that they had the principal responsibility for the overall health, wellbeing, and quality of life for their child – just like they had felt when the child lived at home.

"[…]there will always be this worry. There will always be a…you always feel a responsibility. Also, because there are many things she can't manage herself and stuff like that. So, it will always be there".

(Mother interview 11)

Even after they were no longer responsible for the daily care, some of the parents felt they needed to be constantly available for urgent matters regarding their child. Therefore, they always kept their mobile phone on and with them, and rarely turned it off.

Although the parents were relieved from the exhausting and time-consuming daily caregiving, some said they had experienced a feeling of complete exhaustion that had lasted for years even after the child had moved out. In some cases, this feeling of exhaustion had been so profound that even visiting the child or when having the child at home for visits could feel unsufferable and had made them abstain from it. This was especially the case for parents who described that they had performed way over their capacity of mental resources for years when the child was living in the parental home.

"And sometimes I have also given it a low priority [having the child home for visits] because I think that it has been, I think it has been difficult. So, I think that I haven't felt super well myself, and then it has been difficult to be able to take her home, and find the energy to have her home[…]…when I, like, first go down this downward spiral, [it's] moving further and further down. Now, it's a long time since I last visited [child's name], so I really have to pull myself together".

(Mother interview 12)

Aging Affecting How Parents and Child Can Spend Time Together

Over the years, the aging of the individuals with RTT could lead to a growing need for physical support e.g., when moving around or changing position. Meanwhile, aging in parents led to a decline in their physical or mental capabilities, making it increasingly difficult for them to meet their child's needs. This could affect the ways the parents and the child could spend time together. As such, none of the older parents lived with their child anymore and, for some, the decline in physical and mental ability over time made it impossible for them to have their child home overnight or even for short visits.

> *"Dad: Yeah, well, our parenting role will be unchanged [after the dad has become sick] with these limitations that might come. Naturally, of course, there's nothing else for it. And it can become something like: Oh, now she can't come home every third weekend, she can only come once a month and […].*
>
> *Mom:…and then we will visit her here [at the group home], right. And then, ehm, yeah we must take it as it comes."*
>
> (Parents interview 4)

For some, these changes brought feelings of guilt and sadness about not being able to be there for their child or spend time together as they used to do. Others just considered it a circumstance of life they had to deal with when the time came.

Theme 4: The End of the Life

Fears of the Child Outliving the Parents

When thinking about the future, the parents feared that the child would outlive them, because they were certain no one could substitute their parenting role and engage with their child the way they had done. Some parents were reluctant to ask others to take over the responsibility for the child, because they felt it was too heavy a task to ask of others. Some hoped a family member would voluntarily assume this responsibility. However, they understood that the family member probably also had other commitments and thus could not visit or care for the child as frequently, nor advocate for the child with the same dedication as the parents had done. Therefore, the parents feared that their passing away before the child would have consequences for the child's wellbeing and quality of life. Thinking about this scenario could be rather painful for the parents.

> *"Mom: […]I think I put it aside a bit [thinking about passing away before the child] because it is one of those 'phew[overwhelming]-feelings'. It really hurts when you truly feel inside…you might be able to open up and say, 'Lets open up a little bit here,' but then we just tuck it away in a drawer and try to hide it*

for a bit, right. Yeah, because it's[…] it's not something you want to delve too much into."

(Mother interview 12)

This fear of the child outliving the parents made some of them aware of their own health. Sometimes, it could give rise to worries of becoming seriously ill, even in cases where the parents were not particularly old.

"Then there is also this where I sometimes wonder, would I have been like this if I hadn't had [name of child], that I now have to panic about becoming sick myself?"

(Mother interview 2)

Relating to a Potential Loss of the Child

The fear of the child outliving the parents induced the contrary hope: i.e. the hope of outliving the child, even though they knew that it would be a massive loss for them. It was a loss and grief they were willing to go through for the sake of their child and the chances of the child having a good life. However, there was a difference in the way the parents reflected on and talked about this loss depending on the life phase they were going through. Parents who were younger or parents whose child did not have any severe medical problems, expressed a fear of losing their child at an early age.

"We absolutely won't lose her, you see. But we will absolutely not have that she loses us as well."

(Father interview 5)

On the contrary, some of the older parents or parents whose child had severe medical problems seemed to be more at ease with the thought of this loss. For example, they spoke more explicitly about the possibility of the child dying and expressed a hope that the child's death would be peaceful and without heavy interventions. These parents also expressed that, although it would be a massive loss for them, it would be acceptable if the child died now, because they felt that their child had had a good life.

"Mom: I don't hope that [name of child] becomes particularly old. I hope that one morning she just doesn't breathe anymore. And that they don't employ heavy-handed methods….

Interviewer: In relation to resuscitation?

Mom: Yes[…] And I do think…it would be awful if her life became worse than today, just because someone has thought that she should be resuscitated."

(Mother interview 2)

Repeating Experiences

Theme 5: Interconnected Emotional Wellbeing

Witnessing the Child'S Struggles

In general, the parents expressed that their emotional wellbeing was intimately interconnected to their child's. As such, the parents felt that if their child was thriving, so were they.

"I think we are set up in such a way that if it works for [child's name], then it works better for us. Then there is automatically quality of life for us."

(Father interview 10)

The interconnectedness of their wellbeing was especially prevalent among parents of children living at home. If their child was going through a period of not feeling well or was struggling, e.g., was in pain, having seizures or screaming spells, it affected the parents' wellbeing negatively, as it was hard for them to witness, and could make them sad, worried, or frustrated. If the parents could not identify what was wrong when the child went through a hard time, or they could not relieve the child from the suffering, it could be even harder on the parents and cause considerable frustrations.

Knowing about the child's failure to thrive.

If the child was living at a group home, the parents' wellbeing could still be affected by the child's wellbeing. However, the difference was that the parents were affected by the child's general wellbeing rather than its daily wellbeing. For instance, if the parents felt that the child failed to thrive in the group home, this could give rise to feelings of worry, guilt, stress, frustration, sleeplessness, and powerlessness. In contrast, feeling that the child was thriving could make the parents feel calm.

"Well it has done so much for me, I would say. I sleep well at night [after the child has moved from a bad to a good group home]. I don't have this knot of worries in my stomach, I don't feel bad at any time, I'm feeling very well, I would say. And I'm so happy for her."

(Mother interview 2)

Theme 6: Distressing Alterations

Interrupted Routines

When considerable alterations in the child's daily life happened – e.g., moving from kindergarten to school, or if there was a replacement in the closest staff – a new vulnerable situation arose for the parents. They worried about having to leave the responsibility in the hands of new professionals, whom they did not know anything about, including their competencies to understand the child's wants and needs. For several parents, this could often give rise to anxious and stressful thoughts and feelings.

> *"[…] I remember it as every time there was a shift[…] then I was in this state that I think was draining energy-wise, and I've been a bit emotionally unstable, and have cried and been very frustrated, and thought that it was difficult and hard".*
>
> (Mother interview 12)

Facing Illness and Deterioration in the Child

Other critical events, such as the child falling sick, being hospitalized, or experiencing changes in the general condition, affected the parents over the years. Some parents had experienced their child's condition becoming life-threatening. In such situations, everything else in their life, apart from the child, was set on hold. Meanwhile, the parents tried to cope with their feelings of fear, sorrow, anger, and hope.

> *"Interviewer: And how did you handle it as a family at that time, when you didn't really know whether she would survive or not?*
>
> *Dad: I really don't know. I almost can't answer that, because I've practically repressed it all. It was really damned hard."*
>
> *Mom: Yes, but…but I don't know. I think that actually, you are sort of…ehm… well, the brain is put on standby or something like that….*
>
> *Dad: We didn't sleep for…Well, it took at least three weeks before we slept."*
>
> (Parents interview 5)

Furthermore, a decline in the child's health or the appearance of comorbidities could also affect the parents and take a toll on their emotional wellbeing.

> *"Now, where the epilepsy unfortunately returned after four years[…] It* ***completely*** *stressed me out, and I got worried[…] I really think that it's unpleasant that it has returned. Even though she doesn't have these severe [seizures]… ".*

(Mother interview 2)

Theme 7: Engaging with Professionals Taking Care of Their Child

Sharing the Responsibility with Professionals

Leaving the responsibility to professionals was often set up with the purpose of relieving some of the caregiving responsibilities from the parents, e.g., in respite, schools, with home care assistants, etc. However, leaving the responsibility to others sometimes made the parents feel worried and vulnerable, especially if they had experienced that the care delivered did not live up to their standards. So, if the parents felt that the professionals were competent, leaving the responsibility to them was perceived as a support. On the other hand, if the parents felt that the professionals were incompetent, leaving the responsibility to them instead became emotionally straining.

"Dad: It's a bit ambivalent [having her in respite].

Mom: I think it's difficult. It's difficult because they make so many mistakes. I didn't think it was that difficult before, but because something like she's arriving at school [in a bus] without being buckled up, and where she was almost hanging in the seat belt […] It is something like this that makes me insecure [about having the child in respite]."

(Parents interview 7)

Supervising the Professionals

If the relationship between the parents and the professionals was grounded in mutual trust, the parents took on a supervising role in relation to their child's care. In this dynamic, professionals sought feedback or advice from the parents when uncertainties about some aspects of the care arose, which the parents found satisfactory. However, when there was a change in personnel or if the child transitioned to a new setting, such as moving from kindergarten to school, the parents involuntarily often became those who had to transfer knowledge about the child to the new personnel or setting. This was something some parents found frustrating being responsible for. Especially, the frustration grew bigger over the years when they had to do it over and over again.

If the relationship between the parents and the professionals was based on mistrust, the parents felt they had to be more vigilant and controlling in their supervising role.

"Dad: We experienced that some nurses gave her some morphine, and we knew that she was allergic, but it was just that no one had asked us, which meant that, from then on, we just stayed there.

Mom: We just sat there at the bedside.

[…].

Dad: Yes, and, ehm, they [doctors and nurses] didn't get to do anything without us asking what it was, and why, and what it meant."

(Parents interview 5)

Some parents described they did not like having to take on the vigilant role, but they felt they had to do it for the sake of their child. Therefore, they often found this role to be mentally and emotionally draining, especially if they had to do it time and time again over the years. After adopting a vigilant role, the parents could find it difficult to relinquish it, because rebuilding trust in professionals took time. Consequently, parents sometimes carried their negative experiences with them into new contexts, leading them to be suspicious and vigilant from the beginning or to become so very quickly.

Putting the Foot down

The parents knew they sometimes had to compromise on the care or decisions made by professionals. However, when they found them to be inappropriate or potentially harmful for their child, the parents felt they had to put their foot down and insist on an alternative approach.

"I didn't get any clear messages [when the child was sick with pneumonia at the group home]. And then I find her down there [at the group home]. I've never seen anything like that. No, I said. Go out and call an ambulance. It has to be right now!"

(Mother interview 3)

These situations were found to be hard and challenging for the parents and affected their future trust in the professionals. This was especially true when the child's health was at risk, and even more so if the professionals in return questioned the decisions made by the parents.

Theme 8: Managing the Social Services System

Struggling and Fighting

Many parents had experienced positive encounters with their social worker and the social services system. However, most parents used the word 'fight' to describe the encounters and collaboration with both. It was a general experience among the parents that they were met by social workers with suspicion when they applied for help and support, and they felt they had to justify and argue for every little thing they

applied for. Besides being time-consuming, the parents found these experiences very frustrating and emotionally draining. They perceived the social services system as inhumane when it failed to acknowledge their needs and struggles to manage their everyday lives as parents and the challenges they and their child faced. The parents felt that social workers were not supportive allies. Instead, they viewed them as gatekeepers of the social services system, and felt that the social workers focused on minimizing costs.

> "*Well, we just talk on behalf of [name of the child]'s [and her] needs. And then it becomes completely neglected. It is almost interpreted as if you're lying. […] Something that is completely clearly beneficial for [name of child][…], it is taken away from you. And it's therefore that the psychological strain on us, and that, how would you put it, oh yes, it's a completely rude and outrageous treatment!*"
>
> (Father interview 13)

Gaining Experiences on How to Deal with the Social Services System

At the beginning of their parental life, the parents felt inexperienced in navigating the social services system and often felt misled. Over the years and through repeating interactions, they gradually gained experience and learned to better navigate the system, and some developed strategies that increased their likelihood of getting grants.

> "*And it is also here that I learned that, when we communicate, ehm, with public authorities, then we peel off all emotions, and then we only put facts on the table….*"
>
> (Mother interview 12)

Despite the growing experiences over the years, the parents did not feel it became less time-consuming, mentally draining, or frustrating for them to engage with the social services system. When the child had moved out, some parents found it was still time-consuming to engage with the system, while others did not.

Discussion

Through this study we found that, over time, being a parent to an individual with RTT had a cumulative effect on the parents and their wellbeing, arising from the extensive and demanding care, ongoing engagement with professionals, navigating social services, and the constant need to be available for their child. Some of the experiences affecting the parents and their wellbeing were linked to a specific life phase, while others were linked to experiences the parents repeatedly had to go through over the

years. Furthermore, the parents' own wellbeing remained closely interconnected to their child's wellbeing, regardless of whether the child lived at the parental home or in a group home. So, if the parents found that the child was not thriving or was suffering it fundamentally reduced their own wellbeing.

When the child with RTT lived at home, this was the most demanding and comprehensive life phase, in terms of caregiving, time use, and responsibilities, linked to the high number of daily and strenuous caregiving tasks. The strain of having the child living at home, is in accordance with other studies about parents of children with multiple disabilities (Currie & Szabo, 2019; Geuze & Goossensen, 2021; Williamson, 2019). In some of these studies, the parents described never having time off and having to manage a broad variety of tasks and responsibilities, including those typically handled by professionals (Currie & Szabo, 2019; Williamson, 2019). In the study by Geuze & Goossensen, the parents described their daily life as unpredictable (Geuze & Goossensen, 2021). Similarly, the parents in our current study described an unpredictable daily life, having to respond to sudden needs, challenges, emergencies, or changes throughout the day. Additionally, the parents described their daily life as involving the same comprehensive, demanding, and time-consuming caregiving tasks. As such, the results of our study showed, that the combination of always having to be prepared to manage un-predictabilities in combination with repeatedly performing the same demanding caregiving tasks appeared to deplete the parents' mental resources over the years.

Furthermore, our study highlighted that parents' feelings of burden was not solely attributed to the caregiving responsibilities related to their child with RTT. In addition to managing the complex and demanding care of their child, the parents also had to navigate a range of competing responsibilities inherent to life in general, including caring for siblings, aging grandparents, or dealing with spouse's health issues. These were additional stressors that together with the stressors of caring for the individual with RTT could affect and challenge the parents and their wellbeing. A literature review shows that the work-family balance of parents of children with disabilities was affected by factors such as the age and severity of the child's disabilities, number of children in the family, and the parents' relationship status (Brown & Clark, 2017). Juggling the numerous and challenging responsibilities can result in what Brown and Clark referred to as 'quantitative role overload' where the parents do not have enough time for all their tasks and responsibilities (Brown & Clark, 2017). These findings together with the findings of our study underscore the importance of adopting a holistic perspective when considering support interventions for the parents. Professionals providing support should recognize that the wellbeing of these parents is affected by multiple intersecting factors and responsibilities not necessarily stemming from the parenting responsibilities of their child with RTT alone. As such, we would suggest that professionals should not only explore and address the direct caregiving challenges but also the broader life circumstances of the parents and the family, when providing support.

When the individual with RTT moved out of the parental home, we found that parents remained engaged in multiple tasks and responsibilities, such as applying for services, interacting with professionals—including healthcare providers—being

available for emergencies, and making decisions on behalf of their child. Thus, their caregiving role did not cease but rather transformed into a different set of responsibilities. This ongoing parental engagement, even after the child had grown up and moved out, has also been documented in previous research (Iacono et al., 2016; Walker & Hutchinson, 2019). In addition, the life phase view of our study allowed the parents to describe their experiences over the years and it became evident that the demands of their caregiving when the child lived at home had long-term effects on their wellbeing. For instance, some parents reported experiencing profound exhaustion for years after their child had moved out. These findings highlight that parenting a child with multiple disabilities such as RTT is a lifelong process that evolves over time but continues to affect parents' wellbeing in significant and detrimental ways.

We argue that the demanding and comprehensive caregiving responsibilities the parents must carry out for an extensive number of years is comparable to the work performed by professional caregivers such as nurses or care assistants. Like professionals, parents engage in complex medical, emotional, and physical care tasks, often requiring high levels of skill, endurance, and emotional regulation (Geuze & Goossensen, 2019; Krantz et al., 2022). This recognition may allow us to better understand the psychological mechanisms affecting the parents and challenge their wellbeing by looking at how care professionals can be affected by their job. Compassion fatigue is a concept that describes psychological mechanisms experienced by professionals that are working with people who are suffering, seriously ill, traumatized or dying (Blair, 2017; Figley, 1995, 1998; Lynch & Lobo, 2012; Sabo, 2011). It develops gradually as a result of prolonged exposure to the suffering of others, combined with the emotional and physical demands of caregiving. It arises when caregivers repeatedly empathize with those in suffering without sufficient time to recover, leading to cumulative stress and exhaustion. Over time, this can result in emotional numbness, decreased empathy, and burnout, ultimately impairing the caregiver's wellbeing and effectiveness (Figley, 1995, 1998).

Strategies to reduce the risk of experiencing compassion fatigue in professional caregivers is through clearly defined work boundaries, mindfulness, and selfcare, including getting enough sleep (Partlak Günüşen et al., 2022; Sullivan et al., 2019). Furthermore, the carers' ability and possibilities of detaching from the caregiver relation diminish the risk of developing compassion fatigue (Blair, 2017; Day & Anderson, 2011). Parents of individuals with RTT do not operate within the same formal frameworks, and their caregiving responsibilities extend far beyond what is typically expected in professional settings. They have no clear working boundaries, as the lines between providing care for their child and their personal life become blurred when they must always be prepared to meet the child's needs. With over 80% of individuals with RTT experiencing sleep disturbances (Tascini et al., 2022), caring for a child with RTT is a 24/7 responsibility. As parents, they are continuously responding to their child's difficulties and suffering, without the ability to detach from it.

The counterpart to compassion fatigue is compassion satisfaction, which refers to the feeling of pleasure a caregiver gains when providing care (Lynch et al., 2018; Stamm, 2010). Some parents of individuals with RTT do experience rewarding aspects of caregiving (Adams et al., 2018; Cianfaglione et al., 2015, 2017; Retzlaff,

2007; Williamson, 2019), as did some of the parents in our study, which may help reduce their risk of developing compassion fatigue. However, the key question is how to support parents in enhancing their compassion satisfaction and mitigate their risk of compassion fatigue when the caregiving they are providing takes place in their private setting and is inherently tied to their parenting role.

One way to achieve this could be by providing adequate in-home and/or out-of-home respite care while the child is still living in the parental home, tailored to the specific needs of each family. Another approach is to offer regular supervision to help the parents manage emotional distress, as well as interventions that have been shown to support the wellbeing of parents of individuals with disabilities, such as Acceptance and Commitment Therapy (Chua & Shorey, 2022; Irwin et al., 2019; Schlebusch et al., 2024). Peer support has also been found to have a positive impact on parental wellbeing (Blake et al., 2019; Chakraborti et al., 2021; Fu et al., 2023), suggesting that facilitating access to peer support networks may help reduce parents' risk of developing compassion fatigue. Since parents encounter different challenges depending on their own life phase and that of their child, peer support groups should ideally be structured to include parents experiencing similar phases of their parenting journey.

Strengths and Limitations

The interviewer's years of clinical experience in CRS provided a strong preunderstanding of the field, shaping the questions asked during the interviews. As a result, parents did not need to explain many aspects of their child's diagnosis, the social system, or the healthcare system. This allowed them to focus solely on sharing their experiences as parents without having to contextualize their circumstances. However, the interviewer's prior knowledge may have led to fewer follow-up questions on topics she was already familiar with, potentially overlooking details that might be less apparent to those outside the field. All the way through the study, the interviewer documented and reflected on such preunderstandings, and discussed them and their impacts on the study in the interdisciplinary research group and the stakeholder group.

We gained in-depth and rich descriptions from both mothers and fathers. We included parents in different phases of their life, marital status, living situations and of different sexes. However, when asking the parents about experiences taking place over many years, their recollection of their experiences may be limited, and relevant experiences may be omitted. Parent couples living together could choose to be interviewed together or separately, and all chose to be interviewed together. This may have made them more comfortable during the interview but could also have influenced their narratives. Although we encouraged them to share individual perspectives, the interviews often resulted in one shared narrative. However, interviewing together might have strengthened the narratives, as couples could support each other to feeling more secure, and recall their early years as parents more accurately (Taylor & de Vocht, 2011).

Conclusion

Our findings indicate that the parents feel a lifelong principal responsibility for the health, wellbeing, and quality of life of their child, even after the child grows up or moves out of the parental home. Further, the parents' emotional wellbeing is interconnected to that of their child.

Depending on their current life phase and other competing responsibilities, the parents seem to have diverse emotional and practical challenges. Therefore, they may require different kinds of support based on the life phase they are going through. Some challenges in relation to their parental role and responsibilities presented themselves again and again across life phases, and such recurring experiences depleted the parents' mental resources over time.

Future research should explore strategies for parents to develop and maintain sustainability in their wellbeing, and ways in which professionals can support them in this. Such efforts would benefit not only the parents but also the child and its health, wellbeing, and quality of life.

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Declarations

Conflict of interest The authors declare no competing interests.

Ethical Approval The required approvals to conduct the interviews for this study was obtained from the Danish Data Protection Agency of the Capital Region (reference no. P-2022-754) and the National Committee for Health Research Ethics (reference no.F-23008139) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent All the participants signed an informed consent form.

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